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## ABSTRACT

Retrospective accounts of the nature of adolescence as experienced by mildly handicapped individuals were gathered through indepth conversations and interviews over an 18 month period with 48 mildly retarded adults (ages 22 to 60) living independently in the community. Structured life history interviews were also conducted with parents or other close family members of 37 of the 46 subjects. Questions focused on the impact of the handicapped child on the family and the child's developmental history, including behavioral characteristics during the teen years. For 85% of Ss, adolescence was seen as a time of acute stress in the two primary areas of parent/child relations and identity issues. Serious behavior problems were reported for 61% of Ss. The following contributing factors to a high incidence of emotional problems were reported: (1) absence of normative expectations by parents; (2) lack of a peer support network; and (3) adolescent emotional over-responsiveness, linked to a deficit in the socialization of emotionality. Consistent relationships between patterns of parenting behavior and the symptomatic behavior of the retarded adolescent were noted. (JW)

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**Coping With Adolescence:**

**Perspectives of Retarded Individuals and Their Family**

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It is generally held that adolescence is a time of increased turmoil and stress as the adolescent, too old to be treated as a child and too young to have the rights of an adult, faces a multiplicity of problems in making adjustments to parents, peers, school, and sex (Eme, Haisiak, & Goodale, 1979; Gaier, 1969; Hill, 1980; Jersild, 1963). Adolescents are troubled about their own identity-- who they are, their sex roles, their place in the scheme of things-- and about their need to shed family dependencies and exert control over their life. Their search for self-definition and increasing independence leads to moments of confusion, anxiety, and anger as they experience contending drives that work against each other. They have a desire to assert their own individuality and also a great need to conform; they want to be treated as adults and yet also to be protected.

Jessor and Jessor (1977) describe adolescence as the time of movement away from the confinement of the family context and of entry into those roles that are available in the larger social environment. This dual task of "breaking away and forging a new identity" generates family stress as both parents and child experience feelings of dissonance. Nonetheless, the majority of parents respond to their maturing child with some degree of recognition and accomodation. They provide increased support for independence by initially giving their sons or daughters responsibility in terms of material things such as choosing their own clothes and spending their allowance, and then by gradually allowing them to accept responsibility for more important areas of life such as decisions about relations with peers and job choices.

As mentally retarded children approach adolescence, they experience the same biological changes and drives as normal youngsters (Irwin, 1977). For retarded young persons, however, the problems associated with adolescence are

exacerbated by their handicap. In contrast to normal teenagers who struggle to determine their relationship to society and the roles and lifestyles they will assume, mentally retarded adolescents experience more conflicting answers to the questions, "Who am I?" "Will I live independently?" "What kind of work will I do?" "Will I marry and raise a family?" (Abramson, Ash, & Nash, 1979; Paulson & Stone, 1973).

Adding to the identity confusion of the retarded child is parental anxiety which increases as the child matures and remains unprepared for the roles an adult is expected to fill. Since parents are uncertain of the adult demands to be placed upon their son or daughter, they are unsure of what instrumental competencies to develop in their handicapped offspring. Further, while they may recognize that normal teenagers need support and control as well as opportunity for experimentation, they are more ambivalent about how to handle their retarded child. The concern and fear that parents feel are evident in the words of the parent of one mildly retarded child:

As she grew up her father and I had worried about what would become of her when that time had arrived and because no one could tell us our imaginations ran wild. We pictured her sitting in the dreary day-room of a state hospital drooling over a half completed pot-holder or we saw her following us around the house in our dotage becoming a burden to her younger sister and brother when we died (Kaufman, 1980).

The nature of adolescence as experienced by the handicapped individual has been largely ignored by the research community. In what follows, we shall attempt to report the kinds of problems and concerns that mildly retarded individuals describe as having disturbed them as adolescents, the array of problem behaviors exhibited by these retarded young persons, and the strategies

adopted by parents to cope with their son's or daughter's "crisis of adolescence". Although we rely upon retrospective accounts of the adolescent period from sample members themselves and from parents or other close family members, we are well aware of the problems inherent in these reconstructions of the past. However, rather than judging these selected memories in terms of their truth or falseness, we view them as a vehicle through which an understanding can be gained of how these retarded individuals conceptualize past experiences and the saliency of these experiences to their self-identities (Langness & Frank, 1981; Koegel, 1978).

#### Method

##### Sample

Over an 18 month period, beginning in July, 1980, 46 individuals have been studied by intensive, naturalistic methods. One of the major goals of this research was to understand the personal and social adjustment of mildly retarded adults living independently in the community. More specifically, we sought to document the life experiences and coping responses of sample members as they adapt to everyday living. Sample members were located through a variety of public agencies serving the developmentally disabled including California Regional Centers, residential facilities, sheltered workshops, social groups, and training programs. These sample members ranged in age from 22 to 60 years (mean = 35.35; s.d. = 10.08); there were 25 males and 21 females; 33 were Anglo and two were hispanic; 21 were single; the remainder married, separated or divorced; 17 were unemployed, 9 were in sheltered workshops and 20 in competitive jobs. All of the 46 sample members were specifically selected so as to be free from major behavioral or emotional problems; although it was later learned that one sample member did have a history of psychological disturbance. IQ data were not available for all of the sample members, but all were

individuals who had been classified as mildly retarded at some point in their development by a component of the service delivery system and all had been recommended for or placed in special education classes during their school years. For the 28 sample members for whom IQ scores were obtainable, most had scores within the 60 to 69 range; the mean IQ was 67.

Most sample members spent their childhood years living at home with family members; however, seven spent some time in a state institution; five attended private special education residential schools for various periods of time; and three resided in foster care or board and care homes from very young ages. While the socio-economic status of the families of the sample members was not a controlled variable, the parents of all but four individuals were middle class; the remaining four sample members were from lower SES families.

#### Procedure

The principal means of data collection was a form of participant observation. This procedure allows for the field researcher and sample member to engage in intensive interactions over a prolonged period of time. During that time discussions take place and observations are made as the sample member is involved in various typical activities. Given the continuing and long term nature of the contact, close relationships develop between researcher and sample member which result in intimate conversations on a range of topics.

A field researcher was assigned to each sample member and visits were scheduled at least once a month. Over the course of 18 months, these contacts took place in the homes of the sample members as well as in other settings to permit observation of the individual in a variety of natural settings. More focused data collection was also undertaken by field researchers who encouraged sample members to recount childhood and adolescent experiences. Researchers were instructed to use opportunities which either occurred naturally during the

course of a visit or could be eased into through indirect questioning. Tape recordings of conversations and the researcher's notes on other observations were then used to construct a detailed narrative account of each contact. The resulting fieldnotes have become extremely detailed, allowing us to examine a number of features of the sample member's lives.

Structured life history interviews were also conducted with parents or other close family members of 37 sample members which covered the impact of the handicapped child on family members' lives and the developmental history of the handicapped child, as well as school, social, residential and work histories. Family contacts were initiated by field researchers and, in total, 120 questions were asked, typically requiring two or three interview sessions and six to nine hours for completion. A number of questions specifically focused on the adolescent period so that family members were asked to describe the behavioral characteristics of the retarded youth during the teen years in terms of self-control, emotional adjustment and feelings about self, what problem behaviors, if any, the retarded teenager exhibited and how they were managed by parents; in what ways the parent-child relationship changed during the teen years and the characteristics of that relationship, and so forth. For the other nine sample members such information was inaccessible because family members were either deceased or were for other reasons such as poor health, unavailable.

### Results

The reports of sample members indicated that for 85 percent of them, adolescence was a time of acute stress. Two major foci of concern were described as having affected their emotional adjustment: parent/child relations and identity issues. Both are concerns that all adolescents must contend with,



however, many of the complaints expressed by these retarded individuals are somewhat unique to this population (see Table 1).

Insert Table 1 about here

### Parent/Child Relations

A key feature of adolescence is the gradual achievement of emotional and behavioral autonomy from parents and typically involves some amount of parent/child conflict. Therefore that 48 percent of the sample featured the independence/dependence struggle as a major complaint was to be expected. In general, sample members objected to what they considered to be too much interference by parents in their daily lives. They felt that parental attitudes and practices were restrictive and conflicted with other pressures to achieve and become independent. They complained that parents imposed rules governing their conduct, such as curfews requiring them to be home at a certain time, restrictions on who they could associate with or on their telephone usage, and demands for tidiness with regard to appearance or personal property. They resented parental overprotectiveness and reluctance to permit them to venture into new situations or experience normative activities. And most felt that parents treated them like children, having made all decisions for them and dictated what they were to do.

### Identity Issues

The central task of adolescence is self-definition, the development of a person's ideas and attitudes about who and what he or she is. Erikson (1968) describes it as a time of seeing oneself and one's relation to others in a more differentiated and integrated way; in terms of how one perceives oneself in comparison to others as well as how one perceives the way in which others judge

him or her. For 76 percent of our sample members, it was during the adolescent period that they became aware of their "differentness" and the effect that their social identity was having on their life. Two sets of experiences provided input into their developing sense of self: expectancy-performance and acceptance-rejection.

In terms of expectancy-performance, 48 percent of the sample reported that adolescence was a time in which they had to come to terms with the realities of their handicap. Their deficits were most likely to be perceived in terms of school performance. They were disturbed by their enrollment in special classes, their lack of achievement in math, reading and other such subjects, their slowness in grasping new material. They began to identify themselves for the first time as slow learners and they felt inadequate, as though they were "nothing".

Many had normative expectations for themselves and became frustrated when they realized that their limitations were hindering the attainment of their goals. They wanted to do the same kinds of things they saw their siblings and nonhandicapped age peers doing--graduating from high school, dating, getting a job, moving out on their own-- but had difficulty trying to keep up. They became jealous as they saw their younger siblings surpass them and accomplish things that they had yet to achieve.

In terms of acceptance-rejection, 61 percent of the sample members reported having experienced some form of rejection either by family members or peers. Some sample members described having been aware that they were a disappointment to their parents. They perceived their parents "partiality to siblings," expressed in differential treatment, as evidence that their parents held their nonhandicapped sisters or brothers in higher regard than them. They interpreted being sent away to school while their siblings continued to live at home, the

different standards of behavior which parents applied to them and their siblings, and the different manner by which parents spoke to each of them as indications that they were not loved as much as their sisters or brothers.

Some sample members also reported rejection by siblings. In addition to reports of not getting along with their nonhandicapped sister or brother and frequent fighting, they described how their sibling often criticized them for not doing more than they did. They complained that their siblings had not totally accepted them and would intentionally hurt their feelings by calling them retarded.

Some form of rejection by peers was described by almost half of the sample. Of these, 90 percent reported being teased and taunted by schoolmates and neighborhood kids; some were occasionally beat up as well. Twenty-five percent regretted having no friends or close associates with whom to share their free time. Another 25 percent were disappointed that they had had no boyfriend or girlfriend as their agemates had. The feelings of most of these sample members were summed up in the statement of one young man: "You were looked down upon as a person with not too much intelligence or smarts and what people were trying to tell you was 'too bad you couldn't live in our world and too bad you couldn't be and act like us.' I felt very much left out of it."

#### Problem Behaviors

There was a broad spectrum of problem behaviors that characterized the retarded individual during the adolescent years. From parent reports and reports by sample members themselves, it appears that in addition to increased tension and emotional over-responsiveness, 61 percent of these young persons had serious behavioral reactions (see Table 1).

The more serious problem behaviors included: temper tantrums, violent and destructive behavior, antisocial behavior, use of drugs or alcohol, homosexuality, rebellious behavior, withdrawal, and self-abusive behavior. Most of these individuals had not been problems for their parents until the onset of adolescence, but at that time parents detected increased nervousness, obstinance, and/or hostility in their handicapped son or daughter. Twelve sample members reacted by throwing temper tantrums. Some had low frustration thresholds and blew up frequently; others seemed to let their frustrations build over time and periodically exploded. Most screamed and yelled and occasionally threatened; five were violent and destructive. Of those, four directed their hostility to family members or their property. For example, one young man threw his dad's transistor radio in the bathtub, tore up his mom's flower bed, stuffed up the toilet bowl on numerous occasions, and the like. A fifth smashed models from his treasured airplane and boat collection. The increasing frustration of one sample member eventually led to a breakdown which required hospitalization for a short time.

Seven of the sample members committed minor acts of deviance. Two young women were petty shoplifters: one took trinkets from the local 7-11 store, the other stole record albums as all her friends were doing at the time. One young man charged \$90 worth of calls to another telephone number; three young men were picked up by the police, each for molesting a younger child; and one sample member repeatedly committed anti-social acts (the nature of which he is ashamed to reveal) until his parole officer finally had him placed in Porterville State Hospital. In addition, other minor violations included the regular use of marijuana and occasional "uppers" by three sample members, the daily consumption of a sizeable quantity of beer by two young men, and engagement in acts of passive homosexuality by another two young men.

Four sample members responded to parental attempts to control them by rebellious or defiant behavior. One sample member refused to go to school and ran away each time his mother insisted he attend. Another sample member objected to her parents' refusal to permit dating and devised devious ways of sneaking out of the house to meet boys. Two other sample members ignored objections to their choice of friends, whom parents claimed were a bad influence on them. One young man for example, was involved in a "group" attempt to burglarize a car as well as other unlawful activities; one young woman was staying out late, partying a lot, smoking marijuana, and she lifting with her friends.

Seven sample members, anxious or frustrated over pressures placed on them at home and at school, displayed symptoms indicating intrapersonal maladjustment. Four young persons became reclusive and withdrew from contact with peers or others. One, for example, sought solace in bed where she stayed for hours and sometimes days at a time; another showed signs of regression and sucked his thumb and publically masturbated. Two other sample members developed nervous habits and inflicted serious injury on themselves by biting their arms and nails, and one sample member ripped her clothing when she carried on hysterically.

Of the remaining three sample members to whom mild adolescent reactions were attributed, parents mostly complained of their son's or daughter's poor emotional control. They described their children as impatient with themselves and thus easily annoyed or upset over not being able to do what they set out to do. They wanted what all those around them had (such as friends and boy or girl relationship, and were depressed by their inability to attain what they felt they should have. They sulked or cried a lot and were overly sensitive to the least little frustration. For example, one young woman, angry with her sister for spending too much time on the telephone, cut the phone cord in half.

Parental Coping Strategies

Of the 37 families interviewed, 86 percent indicated that they were aware of the problems preoccupying the retarded teenager and, in most cases, had tried to be understanding of their frustration and discontent. Parents attributed their child's adjustment problems to loss of self esteem and blamed inadequate educational programming, rejection by peers, lack of accomplishments, and bleak prospects for the future as probable causes of their negative self-attitude. To handle the acting out or intra-personal problems that ensued, they intervened in ways which they believed were supportive. Some sought professional counsel and therapeutic intervention for their troubled child, some searched for more appropriate schools and training programs, and some kept their vulnerable teenager sheltered in the home. Most parents coped with their son's or daughter's problems within the family context, but in the case of 11 sample members, out-of-home placement--in boarding school, group or foster home, or state hospital--was arranged (see Table 1).

For those that remained in the home, parents mostly sought assistance from resources available in the community. Three sample members were taken for psychological evaluations to determine the seriousness of their problem and to find alternative ways to handle the inappropriate behavior. For example, one parent took his 14 year old son to a counselor for evaluation after he was picked up by the police for molesting a young girl; another parent took her son for an educational and psychological workup when he began to show signs of withdrawal and regression. Five sample members were sent for individual counseling to help them learn more about themselves and to feel better about who and what they are. At least 10 parents maintained close contact with school personnel--counselors, psychologists, vice principals; some for advice on

handling their child's misbehavior, others to monitor the appropriateness of their child's placement or programming. One parent, for instance, had her daughter transferred to another high school after she had developed self-abusive nervous habits, the result of daily harassment by schoolmates. When school ended for these individuals, a number of parents were alarmed at seeing their son or daughter disturbed and vegetating at home and so searched for special programs in vocational training, independent living skills, and so on, or job opportunities to keep them active and to give meaning to their lives. In the case of three sample members, parents were concerned with their child's increased nervousness, the result of peer teasing and pressure from school, and so felt it best to keep them in virtual isolation in the family home. These adolescents spent most of their time watching television and listening to music and ventured out only in the company of their parents.

Of the 11 parents who sought out-of-home placement, most believed that the new setting offered their son or daughter more than they could do for them at home. Alternative solutions had been tried prior to this "final" decision, but none had succeeded in easing their child's adjustment problems. Some parents felt their child needed more structure and discipline than they could provide, some hoped their child would learn to be more independent and to develop social skills, some wanted to lessen the tension between siblings, and still others saw it as respite from the constant demands placed on them and other family members. For example, one young man was so ostracised by neighborhood kids that he had to associate with children half his age in order to have someone to play with. His younger sister was similarly taunted because she had a retarded brother and because he played with "babies". Finally his parents sent him to a residential school so he could be with young boys like himself and so his sister could have some peace. Three of these sample members were placed out of the home by state



order. The parents had been unable to control their child's delinquent or deviant behavior and the courts decided the state hospital was a more effective place for them to receive training.

### Sexuality Issues

Throughout the above discussion the retarded adolescent's increasing sexual drive and awareness of the excitement of a boy-girl relationship is evident. Most, however, received little formal sex education and parents were generally uncomfortable discussing the topic with them. As one sample member complained, "My mother never talked about sex. She told me I'd have to find out when I get married. It was all Greek to me."

Parents, for their part, had to deal with their own anxieties about their child's emerging sexuality and possible pregnancy. Those with daughters were concerned that their child lacked good judgement and was easy prey for higher functioning older men. Indeed, such was the case with five of these young women, two of whom became pregnant. Those with sons had to deal with other kinds of sexual problems. Two young men were having homosexual relations and three had molested younger children. In many cases, parents imposed restrictions upon their retarded adolescent which resulted either in inhibiting or constricting their child's sexual development or in adolescent defiance of the parental controls. For example, some parents tried to discourage or postpone dating as an activity; some carefully scrutinized who their son or daughter chose to socialize with and discouraged relationships they did not approve of; some parents "arranged" for dates for their child and went along as chaperones during the outing. Some parents also took action to prevent pregnancies from occurring. 7 sample members were sterilized at the prospect of their becoming sexually active, and another 14 underwent sterilization operations when marriage was planned.



### Discussion

This study is a first attempt to learn about the adolescent period as experienced by mildly retarded individuals. We relied upon both the perspectives of the retarded persons themselves and on the views of their parents for behavioral descriptions of the handicapped young person. From these accounts it appears that adolescence was indeed a time of storm and stress for this mildly retarded cohort. Almost half of these individuals were frustrated by parental attitudes and practices which they interpreted as nonsupportive, and over three-fourths were distressed by issues of competence and self-definition feeling the implications of their handicap and limitations for the first time. As there was no comparison population included in this research project, nor has a search of the literature revealed comparable data from a sample of nonretarded adolescents, it is not possible to determine the relative frequency or seriousness of the concerns and behaviors described here.

Given the fact that the main criterion for sample selection was independent living status, which implies relatively good personal and social adult adjustment, it would seem unlikely that for this cohort adolescence would have been a highly stressful and problem-ridden time. However, a number of elements in their life experience seem to account for the high incidence of emotional traumata reported in this sample population.

First and foremost, was the absence of normative expectations by the parents of these sample members. Ours is an historical sample, most of whom were raised during a time when little was known about the development of the retarded child. Most parents had been encouraged by doctors to institutionalize their child and then to forget about them. Those parents who chose to ignore such advice found relatively few support services available to them and had to

rely on their own resourcefulness. As such, they reared their handicapped child believing that he or she would always be dependent and in need of support by others, even as adults. They did not expect or prepare him or her to assume adult responsibility or to live independently nor did they envision the parent/child relationship moving toward symmetry as with their nonretarded offspring. In more recent years, however, professionals serving the developmentally disabled have been guided by the principles of normalization and have become more optimistic about the potential for adult achievements. As these retarded individuals were exposed to and influenced by changes in the attitude and policy of delivery system agents and agencies, conflict with parents and frustration with self ensued.

A second major element implicated in high incidence of emotional traumata was the lack of a peer support network. One of the adolescent's primary needs is that of a peer group to assist in the move from dependence to independence. These peer relationships provide the models and the back-up support necessary for achievement of emotional and behavioral separation from parents. For individuals who have difficulty in forming such relationships, there are serious implications for detachment as well as sexuality and intimacy development (Hill, 1980). Such was the case with our retarded sample members. Most did not have an opportunity for involvement with individuals whose experiences and background resembled their own and who were similarly struggling to transform parent/child attachment. As a result, dependence on parents was prolonged and the development of an adult identity was delayed or, in some cases, prevented. Thus the relatively long period of adolescence experienced by these retarded individuals and the concomitant lack of personal autonomy intensified their frustration and magnified adjustment problems.

The third contributing element is the retarded adolescent's apparent emotional over-responsiveness, which appears to be linked to a deficit in the socialization of emotionality. An emotional state is considered a function of both a state of physiological arousal and of a cognition or schemata appropriate to that state of arousal. The cognition provides the framework within which one understands and labels his/her feelings so that, for example, one learns that what one feels when approached by a stranger in a dark alley is "fear" (Schacter & Singer, 1962). In the case of our sample members, it may very well be that when an experience triggered emotion, they lacked the cognitions which determine whether the state of physiological arousal will be labeled as "anger", "joy", "fear", or whatever. They had not yet learned to differentiate between various emotional states and so responded to all states of arousal similarly, by acting out or the like.

Finally, there appear to be consistent relationships between different patterns of parenting behavior and the symptomatic behavior of the retarded adolescent. Three distinctive socialization patterns have previously been identified for this sample population: (Zetlin, Turner, & Winik, in press): Supportive Relationships in which parents encouraged self-sufficiency and independence and worked hard to maximize their handicapped child's self-confidence; Dependent Relationships in which over-protective parents inadvertently promoted dependence and reliance on others throughout the developmental period and into adulthood; and Conflict-Ridden Relationships in which over-regulating parents who had difficulty accepting the handicapping condition, transmitted mixed messages to the retarded child about their abilities and rendered their son or daughter conflict-ridden and dependent. In addition to these variations in parental behavior, the three socialization environments differed in terms of warmth, realistic acceptance of the handicap,

emphasis on normalcy experiences and risk-taking, and attitude toward and treatment of nonhandicapped offspring. Our preliminary findings in the present study indicate that these parenting styles appear to have a differential effect on the nature and occurrence of adolescent adjustment problems. Half of the sample members reared in supportive homes described having been troubled during the adolescent years; 60 percent of those from homes in which dependence was fostered revealed having had problems as teenagers; and all those from conflict-ridden homes reported being distressed and anxious when in their teens. In terms of the kinds of problem behaviors salient among these individuals, temper tantrums and nervous habits were more commonly reported in sample members from supportive homes, temper tantrums accompanied by violence or a tendency toward withdrawal were symptomatic behaviors more typical of dependent sample members, and anti-social forms of behavior including shoplifting and homosexuality were more often found in those from conflict-ridden homes.

In conclusion, it is noteworthy that the issues these retarded individuals perceive to be highly problematic during the teen years--concern with self-definition and autonomy--have become less salient for them as adults. Only in a few cases, mostly those from conflict-ridden homes, does personal identity and parent/child relations continue as central concerns. For most, the achievement of independence, acquiring material possessions, managing their own homes, holding down jobs, and, in some cases marriage, have contributed to their sense of self-worth and thus provided the security to regard those painful issues as behind them, never completely forgotten but no longer an everyday thought.

Footnote

1. This study was part of a larger investigation of personal and social adjustment of retarded persons living in community settings (directed by J. Turner, A. Zetlin and R. Gallimore); the research was supported by NICHD Grant HD 11944-03 to the Socio-Behavioral Research Group, Mental Retardation Research Center, UCLA.

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Table 1

## Percentage Distribution of Concerns and Behaviors of Adolescents and Their Parents

<u>Adolescent Concerns</u> (n=46) <sup>a</sup>	<u>Total Sample</u> 85	<u>Males</u> 46	<u>Females</u> 39
Parent/Child Relations	48	22	26
Identity Issues	76	43	33
Expectancy-Performance	48	26	22
Acceptance-Rejection	61	35	26
<u>Problem Behaviors</u> (n=46) <sup>a</sup>	61	30.5	30.5
Temper Tantrums	26	11	15
Violent and Destructive Behavior	11	9	2
Antisocial Behavior	15	11	4
Use of Drugs/Alcohol	8	4	4
Homosexuality	4	4	0
Rebellious Behavior	8	4	4
Withdrawal	8	4	4
Self-Abusive Behavior	6	0	6
Emotional Over-responsiveness	6	2	4
<u>Parental Coping Strategies</u> (n=37) <sup>b</sup>	86	50	36
Psychological Evaluation	8	5	3
Counseling/Therapy	14	11	3
School or Training Program Involvement	44	25	19
Home Confinement	8	3	5
Out-of-home Placement	31	22	9

<sup>a</sup>  
based on data from all sample members

<sup>b</sup>  
based on data from parents and family members